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ABSTRACT

Effects of children's diagnosis, setting of intervention, and involvement in parent education groups on families of 85 parents of handicapped children were investigated. Significant results were found regarding reported parent-child interaction, early intervention program suggestions, family stress, and both formal and informal family support systems. Parents of children with conditions associated with mental retardation were significantly more likely to report that they did nothing differently with the child as a result of his/her special needs, compared with parents of children with orthopedic impairments who reported doing significantly more physical therapy activities. However, mothers related more typically to their orthopedically impaired children than did mothers of retarded children. Families as a whole and fathers individually reported seeking child care advice from various sources significantly more. The degree of severity of the child's handicap affected daily family life and the family's interaction with their child's treatment program. The age of the child also was associated with significant changes in parent-child interaction patterns. (CL)

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Living with a Handicapped Child: Findings on Families and Early Intervention

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Paper presented at the Annual International Convention of the
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Although a number of research projects have attempted to delineate the effects of having a handicapped child in the family on mothers, fathers, and siblings (Schonell and Watts, 1957; Farber, 1959; Farber, 1960; Farber and Jenne, 1963; Farber and Rykman, 1965; Cummings et al., 1966; Grossman, 1972; Gath, 1972; McAllister et al., 1973; Gath, 1974; Cummings, 1976; Gath, 1978; Hare et al., 1966; Tew and Laurence, 1973; Tew et al., 1974; Shere and Kastenbaum, 1966; Cook, 1963; Margolies and Wortis, 1956; Jensen and Kogan, 1962; Boles, 1959; Klebanoff, 1958; Kogan et al., 1974; Korn, 1969; Korn et al., 1978), few studies have been done on families of very young special needs children, and especially on families receiving early intervention support. What little has been done with families of very young children has focussed primarily on reactions to the birth and on emotional adaptation to having a handicapped child. Research (in this country especially) has often focussed upon the effects of a particular handicapping condition (notably, severe mental retardation) or on a comparison of the effects of types of handicapping conditions.

This research project is designed to compare families who differ in three major ways. (see handout 1) The primary diagnosis of their special needs child can be categorized as either a condition associated with mental retardation or as a condition associated with orthopedic impairment. They are in-

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volved in early intervention programs which are either primarily center-based or primarily home-based. They participate in parent support groups or no support groups are available in their programs.

All families involved in the study had children between the ages of five and thirty-nine months. They had been involved in early intervention programs for at least five months and participated in the program options offered within their catchment areas in a state where statewide services are available. None of the families was dependent on the researchers or their institution for any of the program supports that the family received.

Families of eighty-five children participated in the study (eighty-five mothers, forty-nine fathers). They responded to a mailing and appointments were then arranged. Data was collected through open-ended interview questions and diaries kept by mothers. Only data from the interviews will be reported here. Mothers were interviewed twice; fathers, once. The second interview with mothers which focussed on social networks, family stress, and support systems is the same interview that was conducted with fathers.

The descriptions of families in terms of the major independent variables appear on handout 1. Forty-four families have children whose primary diagnoses are conditions associated with mental retardation; forty-one, with conditions associated with orthopedic impairment. (The figures for fathers are twenty-seven and twenty-two respectively). Diagnoses spanned a wide range of common and less common conditions and syndromes including: Down's Syndrome, various types of cerebral palsy, myelodysplasia, Cornelia de Lange Syndrome, muscular dystrophy, Cri du Chat Syndrome, etc.

Forty-eight families participate in primarily center-based programs; thirty-seven, in primarily home-based programs. (For fathers these figures are twenty-nine and twenty respectively). Forty-four participate in parent sup-

port groups; forty-one have no support groups available to them. (For fathers twenty-seven and twenty-two were the respective figures). In all cases the support groups offered were aimed at mothers and only mothers participated.

Families differed on several other characteristics of note (also found on handout 1). These include: the perceived severity of the child's involvement (measured by mother's report of what the family had been told about the child's condition and what she thought about the presumed severity); age of child; sex of child; intensity of program involvement; length of program involvement; team or individual approach; presence of direct therapist on the early intervention staff; number of children in the family; presence of younger siblings; presence of older siblings; presence of male siblings; maternal employment; maternal education; paternal occupation; paternal education; home owner or renter; and child care arrangements.

Several significant results were found regarding reported parent-child interaction, early intervention program suggestions, family stress, and both formal and informal family support systems. Only a portion of these will be reported in this paper. Families did differ depending upon the type and severity of the child's handicapping condition, the programs in which they participated, and on the many other characteristics analyzed.

Mothers and fathers of children with differing types of handicapping conditions have vastly different experiences with their very young special needs children as well as in other aspects of their daily lives. Mothers of children with conditions associated with mental retardation were significantly more likely to report that they did "nothing" differently with the child as a result of his having special needs ($F=4.10$, $df= 1,75$, $p\leq.05$). Mothers of children with orthopedic impairments often noted exercises as the things that they did differently because their children have special needs. It may be

that the educational activities which programs suggested more for children with conditions associated with mental retardation ($F = 5.09$, $df = 1,77$, $p \leq .05$) are more similar to the activities in which mothers typically engage with their children than are the physical therapy suggestions made significantly more for orthopedically impaired children ($F = 4.34$, $df = 1,77$, $p \leq .05$). It may also be that although mothers of children with conditions associated with mental retardation did not report actually doing significantly more educational activities with their children, mothers of orthopedically impaired children actually did report doing significantly more physical therapy activities during a sample day ($F = 6.67$, $df = 1,73$, $p \leq .015$). They also reported a greater proportion of their joint activities with the child as being physical therapy ($F = 5.40$, $df = 1,71$, $p \leq .025$).

It may not only be that the activities suggested for orthopedically impaired children are more unusual, but also that the mothers are more conscious of following through with these more unusual activities. Since mothers of orthopedically impaired infants also reported receiving significantly more suggestions of activities to do with their children ($F = 4.32$, $df = 1,76$, $p \leq .05$), they may also be responding to the implied greater "difference" that program staff see. That is, if there are more suggestions to be made, it appears that one needs to do more "different" things with an orthopedically impaired child. While this greater number of suggestions may encourage the parent to view the child as more unusual, the reason for the larger number may have nothing to do with the perceived atypicality of dealing with the child. It may, in fact, relate to greater knowledge of remediation techniques for the orthopedically impaired or to a feeling that there is greater hope of remediation for these children than for the mentally retarded.

Fathers were also reported to participate in significantly different activities with their orthopedically impaired children than with their children with conditions associated with mental retardation. Fathers who have children with conditions associated with mental retardation were more likely to play with them in some very typical ways. They participated in significantly more gross motor activities with their children than did fathers whose children are orthopedically impaired ($F = 13.25$, $df = 1,71$ $p \leq .001$). This is not surprising if one considers that orthopedically impaired children may be more difficult to handle easily or that fathers may have been given more specific directions about positioning and handling the orthopedically impaired children. They may also be responding to the reality or the assumption that the children are able to do less motorically or may be less comfortable or more cautious about handling the children. Regardless of the reason, fathers interact in less typical ways with their orthopedically impaired children as well as mothers' seeing themselves as having to do things more atypically if the children are orthopedically impaired.

On the other hand, mothers relate more typically to their orthopedically impaired children in disciplining them. Mothers of orthopedically impaired children report having to discipline their children more than mothers of children with conditions associated with mental retardation ($F = 4.49$, $df = 1,77$, $p \leq .05$). They may also be relating to either their assumptions about their children's abilities, to the children's actual behavior, or to what they have been told about the children. They may assume that their children are more capable of understanding right from wrong than mothers of children with conditions associated with mental retardation assume. The children may, in fact, do more "naughty" things. Or mothers of children with conditions associated with mental retardation may have been told that their children are less capable of abstract reasoning such as differentiating between right and wrong. Mothers

of children who have conditions associated with mental retardation more often described their children as "good babies" who rarely got into mischief. These children may in fact be less curious and less likely to explore new situations and generally "get into things." These types of curious exploration seem the most likely mischief that very young children do.

Within individual interactions with their children both mothers and fathers appear to be responding sensitively to their children's characteristics and needs. In the larger context, their experiences with formal and informal support systems about their special needs children also differ dramatically depending upon the children's identified special needs. This is especially true for fathers. Fathers of children with orthopedic impairments report a greater number of overall supports than do fathers of children with conditions associated with mental retardation ($F = 4.10$, $df = 1,34$, $p \leq .055$). Inter-coder reliability for the number of stress and support units is .992.

Families as a whole and fathers individually report seeking child care advice from various sources significantly more. Both families as a whole ($F = 5.07$, $df = 1,114$, $p < .05$) and fathers individually ($F = 4.86$, $df = 1,36$, $p \leq .05$) report seeking child care advice from professionals significantly more. Fathers also report seeking child care advice from extended family members significantly more ($F = 5.56$, $df = 1,34$, $p \leq .03$). Although fathers appear to interact in more typical ways with their children who have conditions associated with mental retardation, they appear to find it easier to talk about and receive outside support about their children who have orthopedic impairments. This ease of receiving outside support and talking about orthopedically impaired children may result from several sources. It is not unlikely that fathers feel the social stigma of mental retardation more than they feel a stigma attached to orthopedic impairment. The people with whom they interact may find it easier to talk about orthopedic impairments. Seeking professional

advice more may be the result of having more medical questions (planned surgeries, hospitalizations, etc.).

Although fathers differed dramatically in where they sought child care advice depending upon the type of child handicap, mothers were more affected by the severity of the child's disability. Mothers of more severely involved children reported seeking child care advice from an overall greater number of sources than did mothers of children who were less severely involved ($F= 6.56$, $df= 1,75$, $p \leq .025$). They were also more likely to report seeking child care advice from a parent of an older special needs child ($F= 5.42$, $df= 1,72$, $p \leq .025$). This may be the result of their correctly perceiving that parenting a more severely involved child differs more from the typical parenting experience than does parenting a less severely involved child.

It would appear that outside support systems may respond to this difference as well. Families of more severely involved children (both the mothers and the fathers) report receiving significantly greater supports than do families of less severely involved children ($F=3.95$, $df= 1,114$, $p \leq .05$). The mothers of these children were more likely to cite the child's handicap as the family's most important problem when the child is more severely involved ($F= 7.40$, $df= 1, 72$, $p \leq .01$). Of great note here is the fact that not all, nor nearly all the families interviewed saw the family's greatest problem as the child's handicap. A great number of families saw their biggest problem as finances. A large number did not see financial stress as related to the child's handicap since many had good insurance or supplementary security income aid. They attributed their financial problems to inflation, the economic climate, etc.- rather typical family problems. Families of more severely involved children were more likely to see their family life as more affected by the child's handicap, to act differently in their daily lives, and to be treated differently by the programs in which they participated.

Mothers of less severely involved children were more likely to report that they did nothing differently because of the child's special needs ($F=4.30$, $df= 1,77$, $p\leq.05$). They also reported that their early intervention programs suggested significantly more educational activities to be done with their children ($F= 4.37$, $df= 1,77$, $p\leq.05$). This may be seen as collateral support for the interpretation that educational activities are seen by mothers as more typical of the activities in which they would normally engage with their children as was discussed earlier in relation to the child's type of handicapping condition.

Just as the child's type of handicapping condition affected not only how mothers perceived their interactions with their children and the kinds of suggestions that their early intervention programs made but also how parents actually reported interacting with the children, the perceived severity of the child's involvement also affects reported interactions between parents and children. Mothers of more severely involved children more often reported doing the activities suggested by the program daily than did mothers of less severely involved children ($F= 7.53$, $df= 1,72$, $p\leq.01$). They were also significantly less likely to report never doing an activity suggested by the program ($F= 7.44$, $df= 1,72$, $p\leq.01$). This is not surprising when one considers that mothers of less severely involved children may feel that their children do not need as intensive attention in order to develop. Mothers of less severely involved children are also given more educational suggestions and, if these are more typical things to do with young children, they may be less conscious of following through with them as suggestions from the program.

The spontaneous interactions of mothers and fathers with their children also differ depending upon the severity of the child's involvement. Mothers of more severely involved children are more likely to report that they never

have to discipline their children ($F=7.07$, $df= 1,72$, $p\leq.01$). It is likely that these children are less apt to get into mischief. They also reported that fathers interacted less typically and more in keeping with the child's abilities. Fathers did significantly fewer gross motor activities with their children when the children were perceived as more severely involved ($F= 9.09$, $df= 1,78$, $p\leq.01$).

The age of the child also affects how mothers and fathers interact with their children and the types of suggestions that they report early intervention programs making. How mothers and fathers interact with their children is affected by their age in some surprising as well as typical ways. Fathers engaged in significantly fewer activities with the special needs children as the children got older ($F= 4.78$, $df= 1,76$, $p\leq.05$). This may be the result of fathers' responding to the mothers' perceived needs, i.e. that fathers see mothers as needing less help as the children get older and so interact with the children less. Or it may be the result of the disability becoming more apparent and the fathers' withdrawing. Many of the mothers I served in early intervention felt that fathers adapted to having a child with special needs more slowly than mothers so perhaps fathers experience withdrawal at a later time. However, it may be that the fathers are energized by greater family needs during the early phases of the family's adapting to having a handicapped child.

Mothers' spontaneous interactions with their children also changed as the children got older. Older children are the focus of significantly fewer caregiving activities by mothers ($F= 10.10$, $df= 1,75$, $p\leq.005$). Mothers also report having to discipline older children more ($F= 4.38$, $df= 1,79$, $p\leq.05$).

Although fathers interact less with their special needs children as the children get older, the children do fewer activities alone during a sample day as they age ($F=5.49$, $df= 1,77$, $p\leq.025$). Since there is no evidence of an

increase in joint activities with their mothers, it is likely that they participate in more joint activities with siblings, extended family members, and peers. This increase in joint activities for children is in spite of the finding that early intervention staff made significantly fewer suggestions of activities for children as the children got older ($F=4.06$, $df= 1,76$, $p \leq .05$).

It seems likely that the increase in joint activities for children may result in part from other significant adults in the children's lives. As children get older, mothers report an expansion of their primary networks ($F= 4.26$, $df= 1,73$, $p \leq .05$) and that a larger number of people who are important to them are not immediate family members ($F=4.18$, $df= 1,73$, $p \leq .05$). If mothers are expanding their outside networks, it is likely that children are spending a greater amount of time with adults other than their parents and that these adults may have children with whom the special needs children play. It is likely that the lessening caregiving demands which occur as children get older (and were evident in this sample) allow mothers more time, freedom, and energy to seek out other adults outside their families. Although there is no typical sample with which to compare, this finding would indicate that families lessen their social isolation as their special needs children get older- at least within the early years. Whether this speaks to simply a natural process of all parents of very young children, the resilience and recuperative powers of individuals, or the effects of participating in an early intervention program is not known from this study. Regardless of the reason, it is certainly a more positive finding than one might have expected from reading the literature on the social isolation experienced by families who have special needs children.

Throughout this study, one could not help but be impressed by the joys

as well as the pain, the hopes as well as the fears, and the typicality as well as the differences of these families with young children with special needs who so willingly gave of their time to tell us what it is like to live their lives not just what is difficult about having a child with special needs.

Mary A. Moran
CEC 60th Anniversary
International Convention
April 16, 1982

"Living with a Handicapped Child: Findings on Families and Early Intervention"

N= 85 families N= 134 subjects n= 85 mothers n= 49 fathers

MAJOR INDEPENDENT VARIABLES

MR= conditions associated with mental retardation	TYPE OF
OI= conditions associated with orthopedic impairment	HANDICAP
CB= primarily center-based program	PROGRAM
HB= primarily home-based program	TYPE
PG= mother participates in a parent support group	PRESENCE OF
NG= mother does not participate in a support group	PARENT GROUP
Mo= mother	SEX OF
Fa= father	PARENT

MRMo n= 44	MRFa n= 27	CBMo n= 48	CBFa n= 29	PGMo n= 44	PGFa n= 27
OIMo n= 41	OIFa n= 22	HBMo n= 37	HBFa n= 20	NGMo n= 41	NGFa n= 22

OTHER VARIABLES ENTERED INTO REGRESSION ANALYSES

intensity of program involvement
length of program involvement
team or individual approach
presence of direct therapist on EI staff
perceived severity of child's involvement
age of child
sex of child
number of children in family
presence of younger sibs
presence of older sibs
presence of male sibs
maternal employment
maternal education
paternal occupation
paternal education
home owner or renter
child care arrangements

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CEC- April 16, 1982

SIGNIFICANT RESULTS REPORTED

MRMo- report of doing nothing differently because of child's special needs ($F= 4.10$, $df= 1,75$, $p\leq.05$)

MRMo- report more EI suggested educational activities ($F= 5.09$, $df= 1,77$, $p\leq.05$)

OIMo- report more EI suggested physical therapy activities ($F= 4.34$, $df= 1,77$, $p\leq.05$)

OIMo- report doing more joint physical therapy activities ($F= 6.67$, $df= 1,73$, $p\leq.015$).

OIMo- report greater proportion of joint activities with child as physical therapy activities ($F= 5.40$, $df= 1,71$, $p\leq.025$)

OIMo- report more EI suggestions for child ($F= 4.32$, $df= 1,76$, $p\leq.05$)

MRMo- report more gross motor activities done by father with child ($F= 13.25$, $df= 1,71$, $p\leq.001$).

OIMo- report having to discipline the child ($F= 4.49$, $df= 1,77$, $p\leq.05$)

OIFa- report greater overall supports ($F= 4.10$, $df= 1,34$ $p\leq.055$).

OI- report seek professional child care advice more ($F= 5.07$, $df= 1,114$, $p\leq.05$)

OIFa- report seek professional child care advice more ($F=4.86$, $df= 1,36$, $p \leq .05$)

OIFa- report seeking child care advice from extended family members more ($F= 5.56$, $df= 1,34$, $p\leq.03$)

Mo more severe- report seeking child care advice from more sources ($F= 6.56$, $df= 1,75$, $p\leq.025$)

Mo more severe- report seeking child care advice from parent of older special needs child ($F= 5.42$, $df= 1,72$, $p\leq.025$)

More severe- greater number of supports ($F= 3.95$, $df= 1,114$, $p\leq.05$)

Mo more severe- cite child's handicap as family's most important problem ($F= 7.40$, $df= 1,72$, $p\leq.01$)

Mo less severe- report doing nothing differently because of child's special needs ($F= 4.30$, $df= 1,77$, $p\leq.05$)

Mo less severe- report more EI suggested educational activities ($F= 4.37$, $df= 1,77$, $p\leq.05$)

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SIGNIFICANT RESULTS REPORTED

Mo more severe- report more doing EI suggested activities daily ($F = 7.53$, $df = 1,72$, $p \leq .01$)

Mo more severe- report less never doing an EI suggested activity ($F = 7.44$, $df = 1, 72$, $p \leq .01$)

Mo more severe- report more never having to discipline child ($F = 7.07$, $df = 1,72$, $p \leq .01$)

Mo more severe- report fathers doing fewer gross motor activities with child ($F = 9.09$, $df = 1,78$, $p \leq .01$)

Mo older- report fathers doing fewer activities with child ($F = 4.78$, $df = 1, 76$, $p \leq .05$)

Mo older- report fewer joint caregiving activities with child ($F = 10.10$, $df = 1, 75$, $p \leq .005$)

Mo older- report having to discipline child ($F = 4.38$, $df = 1,79$, $p \leq .05$)

Mo older- report fewer activities done alone by child ($F = 5.49$, $df = 1,77$, $p \leq .025$)

Mo older- report fewer EI suggestions made for child ($F = 4.06$, $df = 1,76$, $p \leq .05$)

Mo older- report expansion of social networks ($F = 4.26$, $df = 1,73$, $p \leq .05$)

Mo older- report greater number of significant others not immediate family members ($F = 4.18$, $df = 1,73$, $p \leq .05$)